ASTHO**Report**

Framework for Addressing Ethical Considerations in Infectious Diseases Public Health Wastewater Surveillance

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Executive Summary

Wastewater surveillance (WWS), which measures pathogen levels in wastewater, is vital to evaluate community-level trends and can be used to complement traditional surveillance and interventions. During the COVID-19 pandemic, CDC launched the National Wastewater Surveillance System to coordinate state, tribal, local, and territorial (STLT) public health departments' WWS programs. Until this point, WWS was not being coordinated at the national level. In 2021, 43 public health departments were using funds from CDC to support WWS activities, with a majority of them reporting data to the National Wastewater Surveillance System. As a result of the COVID-19 pandemic response, the use and visibility of wastewater surveillance for infectious disease expanded, illuminating and clarifying the ethical dimensions of WWS in the process.

"Ethics" is sometimes seen as an abstract, difficult, or intimidating topic. By developing this framework, ASTHO aims to bolster public health practitioners' ability to engage in ethical analysis. This report focuses on five ethical values: trust and trustworthiness; reciprocity; justice, equity, and fairness; common good; and privacy. Ethical issues arise when values such as these are challenged or are in tension with each other. This framework outlines questions practitioners can use to analyze a program or decision under consideration.

ASTHO, in consultation with public health ethics and wastewater surveillance subject matter experts from academic institutions and CDC, developed this framework to support STLT health departments; federal public health institutions; and implementing partners, including water utilities, in addressing ethical issues in WWS. ASTHO developed this framework in direct response to recommendations from CDC's Public Health Ethics Committee to address the ethical concerns of privacy, stigma, and data stewardship in WWS. This framework is also responsive to reports from a committee of the National Academies of Sciences, Engineering, and Medicine, convened at CDC's request, to review WWS for uses beyond COVID-19. In its reports the committee noted the importance of addressing ethical dimensions of WWS.

This project included facilitating a discussion with the National Wastewater Surveillance System Centers of Excellence, convening a workgroup, hosting an in-person workshop, and facilitating focus group discussions to center the framework around perspectives and insights from the field. This framework is intended to be one component of a larger ethics strategy that supports WWS ethics preparedness, and includes tools for ethical analysis, case studies, and recommendations about strengthening public health ethics infrastructure.

How was the framework developed?

This framework's focus was informed by deliberations of the ASTHO-convened Ethical National Wastewater Surveillance–Infectious Disease Workgroup (ENWS-ID Workgroup), composed of representatives from health departments, academia, utilities, associations, and tribal health; focus group discussions with subject matter experts; and review of the academic literature, technical reports, and policy documents. The framework is grounded in public health ethics scholarship and existing public health ethics frameworks and guidance, including APHA's Public Health Code of Ethics and the World Health Organization Guidelines on Ethical Issues in Public Health Surveillance.[1,2]

What is the purpose of the framework?

The framework aims to support U.S. STLT health departments, federal public health institutions, and WWS implementing partners, including water utilities, in addressing ethical issues in WWS.

Who is the intended audience for the framework?

The framework is addressed to policymakers, health departments, implementing partners (including water utilities) and other institutions and individuals involved in WWS for infectious diseases.

What is outside the scope of this framework?

The framework is focused solely on WWS for infectious diseases. WWS used for non-infectious disease public health concerns, such as for monitoring licit and illicit substance use, may raise different ethical issues. (However, while not the focus of this framework, this framework's grounding in principles of public health ethics may provide a foundation for addressing WWS for non-infectious disease public health concerns.) In addition, although ethical issues often intersect with legal ones, including in WWS, the legal dimensions of WWS are outside the scope of this framework.

How is the framework organized?

Part 1 provides background on the purpose and scope of the framework, outlines an applied public health ethics approach to values-based ethical analysis and decision-making, discusses the critical role of community engagement in addressing ethical issues, and introduces overarching ethical considerations in WWS in relation to assessing its public health purpose and value. Part 2 describes and provides guidance on key ethical concerns of privacy, stigma, and data stewardship, and provides recommendations about strengthening ethics infrastructure. Finally, the framework includes four appendices. Appendix A contains case studies for discussion and skill-building in ethical analysis; appendix B provides additional details about the process used to develop this document; appendix C provides a quick guide to the framework; and appendix D describes and provides links to resources relevant to ethical issues in WWS.

Part 1

Introduction to Wastewater Surveillance in the U.S.

Encompassing a diverse set of goals and approaches, public health surveillance is “the ongoing, systematic collection, analysis, and interpretation of health-related data with the a priori purpose of preventing or controlling disease or injury, or of identifying unusual events of public health importance, followed by the dissemination and use of information for public health action.”[3] This relationship to public health action provides the justification for doing surveillance and gives rise to its complex ethical challenges.[2,4,5]

With an urgent need for additional surveillance methods in response to the COVID-19 pandemic, particularly ones not reliant on access to or uptake of clinical testing, public health institutions turned to wastewater surveillance (WWS) as a possible tool. WWS offers several potential advantages as a complement to other forms of surveillance and epidemiological information: it does not rely on clinical testing, it may be cost- and time-efficient, and it can be well-suited to detecting community-level epidemiological signals and trends.[6,7,8] Scaling up and expanding COVID-19 WWS required quickly assessing public health value and feasibility. This necessitated rapidly establishing or strengthening new kinds of relationships between STLT health departments and water utilities and also required building infrastructure and fostering collaboration at the local, state, and federal levels. As part of this scale-up, in 2020 CDC established a National Wastewater Surveillance System to coordinate and build capacity for U.S. COVID-19 wastewater surveillance. [9]

Most WWS in the U.S. involves collecting untreated wastewater samples (i.e., sewage and other “used” water from sinks, showers, bathtubs, toilets, washing machines, and similar) collected from a common drainage outlet (i.e., a sampling site—usually a wastewater treatment plant or a point on a sewage line) to analyze the wastewater for chemical or biological markers of health-related conditions.[10,11] Thus, most WWS in the U.S. is restricted to samples from sewered areas.

Until the COVID-19 pandemic, using WWS to monitor infectious diseases was rare in the U.S. and focused on a narrow range of pathogens. For that reason, the recent expansion of WWS has features of an emerging approach or technology, including unresolved scientific issues and the need to better understand its dynamic social and ethical implications.[12] The impact of these qualities associated with emerging technologies may be heightened when WWS is used in response to public health emergencies, for novel pathogens or conditions, and as rapidly evolving technologies like machine learning create both new opportunities and (often, ethical) challenges.[13,14] As the use and visibility of WWS expanded, its ethical dimensions and the concerns from public health policymakers, WWS implementing partners, and communities about access to its benefits and its potential for harm have all come into greater focus.

During the COVID-19 pandemic, WWS proved to be an important tool for tracking emerging variants and contributing information to public health policies and programs.[15] Using WWS data to provide timely, public-facing information through dashboards was both another innovation and also something that raised ethical concerns related to risk communication, privacy, and stigma.[16,17]

As health departments gained experience from and built infrastructure for COVID-19 WWS surveillance, confidence in WWS' potential use for other infectious diseases grew. In a notable example, in October 2022, the National Wastewater Surveillance System rapidly implemented mpox virus surveillance after mpox was detected in the U.S. earlier in the same year. This use of WWS was important both as a strategy to help address a global outbreak and as a demonstration of how WWS infrastructure developed during the COVID-19 pandemic could be leveraged to address other public health emergencies. However, mpox WWS may have the potential to either exacerbate stigma or help mitigate it, underscoring the importance of attending to its ethical dimensions and engaging affected communities.[18,19,20,21,22,23]

Ethics Preparedness and Infrastructure in Wastewater Surveillance

Although public health institutions and professionals regularly encounter ethical issues, they often face challenges in addressing them and engaging in ethical analysis in ways that are both feasible and relevant to the contexts in which they work.[24] Ethics is sometimes seen as separate from routine public health work or as abstract, difficult, or intimidating, and public health professionals may be confused about the knowledge, skills, and resources they need to engage in ethical analysis and problem-solving. Ethics can wrongly be perceived as punitive, a checklist, or predominantly the province of regulatory processes or bodies. In addition, public health institutions and professionals are often short on time and other resources—also a source of ethical dilemmas—making it difficult to engage in ethics preparedness.

As a result, ethical issues are sometimes only addressed when they become significant problems. Yet, investing in ethics preparedness is not just about better addressing crises.[25] Ethics preparedness reflecting strong ethics infrastructure has power to help public health institutions and practitioners prevent problems, make and justify decisions, improve policies and programs, and increase professional satisfaction and morale.

This framework is intended to be one component of a larger ethics strategy that supports WWS ethics preparedness. It includes tools for ethical analysis, case studies, and recommendations about strengthening public health ethics infrastructure.

Applied Public Health Ethics and Values

This framework is grounded in an applied public health ethics perspective. Public health ethics focuses on ethical issues that emerge from the core features of public health, including its focus on population health, its emphasis on prevention, its collection and use of health data, its recognition of the multidimensional nature of the determinants of health, and its prioritization of health equity.[26,27,28,29] These features also make certain ethical values particularly relevant in public health.[27,28]

Surveillance and Informed Consent

As distinct from clinical medicine and human subjects research, individual informed consent is not ethically required for many public health activities for interrelated ethical, practical, and regulatory reasons.[2,30,31] One key reason is because the value of public health activities comes from their large-scale application across populations. Not only would an informed consent process for these large-scale activities be impractical, it would also jeopardize the population-level benefits.

For example, public health surveillance is generally low risk and can confer substantial benefits in understanding and addressing disease spread. Requiring individual informed consent for surveillance has the potential to do harm by preventing surveillance from being timely or done at all. However, this creates heightened obligations to use and protect public health surveillance data in ways that ensure access to its benefits but mitigate potential harms.

Values are beliefs and principles that come from what is especially important, significant, and meaningful and help guide actions and decision making.[28] Many professions, including public health, commit to a set of values that provide a moral justification for their work, such as those found in the APHA Public Health Code of Ethics.[1] This framework for WWS is oriented around five ethical values drawn from established approaches to public health ethics and identified by the Ethical National Wastewater Surveillance–Infectious Disease (ENWS-ID) Workgroup and WWS subject matter experts as particularly relevant to the WWS context. These include trust and trustworthiness; reciprocity; justice, equity, and fairness; common good; and privacy. The table below discusses these ethics values and the relevant governance and scientific values of accountability and transparency, evidentiary standards, and data and resource stewardship.

Of these values, trust and trustworthiness are especially important for WWS. The COVID-19 pandemic may have exacerbated the consequences of mistrust in public health and other institutions, which is longstanding and shaped by structural inequality and injustices—both historical and contemporary— as well as current social and political conditions.[32] Public health institutions have a special responsibility to take actions to establish trust and increase their trustworthiness by ensuring public health ethics values are central to public health policies and programs' design, implementation, and evaluation.[32,33,34]

Table 1. Public Health Ethics, Governance, and Scientific Values

Public Health Ethics Values	Definition in Wastewater Surveillance Context
Trust and trustworthiness	Providing confidence and assurance that WWS decisions and practices are informed by the best available evidence and that actions are in accord with stated public health ethics principles and values.
Reciprocity	Providing public health benefits to the individuals and communities whose data informs WWS or that are burdened by WWS activities.
Justice, equity, and fairness	Ensuring that WWS' benefits and potential harms are distributed fairly and equitably across a population.
Common good	Accepting a shared responsibility to contribute to public health programs, like WWS, that create benefits and contribute to health as a common good.
Privacy	Ensuring that WWS data is safeguarded to maintain anonymity and protect the privacy of individuals and communities.
Governance and Scientific Values	
Accountability and transparency	Ensuring that WWS programs' purpose and intent, anticipated public health actions, and findings are clearly communicated to impacted communities, and that those communities have an opportunity to engage with those conducting WWS activities.
Evidentiary standards	Seeking the best available evidence to initiate, continue, modify, or discontinue a WWS program, and effectively communicating uncertainties or incomplete information.
Data stewardship	Upholding responsibilities to collect, analyze, and store WWS data to safeguard the interests of individuals and communities who contribute to it.
Resource stewardship	Using resources responsibly and advocating for increased investment in WWS capacity and infrastructure where needed.

Public Health Purpose and Public Health Value: Overarching Considerations in Wastewater Surveillance

Public health surveillance is an essential public health activity grounded in the values of trust and trustworthiness; reciprocity; justice, equity, and fairness; common good; and privacy. It is distinct from other ways of learning about the health of a community in two important ways. First, the ethical justifications for public health surveillance depend on aligning its methods and goals with a legitimate and reasoned public health purpose.[4] Legitimate public health purposes for surveillance include protecting, enabling, or enhancing well-being; reducing illness and death; increasing health care access; and reducing health inequities.[2] Health departments should clearly communicate a surveillance program's intent or purpose to the communities it will impact and should justify the program in terms of its public health benefits to them. Further, health departments must feed the information gathered through public health surveillance into public health action that's intended to benefit the population from which the information comes.[4] (Although not all the actions that will be taken from WWS data will be known in advance, public health action is part of the ethical foundation of public health surveillance and part of what distinguishes it from other activities that use wastewater data, such as scientific research.) [4,35]

In this framework, alignment with a legitimate public health purpose is one dimension of public health value. The purpose of a WWS program might be to reduce illness and death through early detection of changing disease trends, but its public health value will depend on other factors that must be considered and weighed against each other. For example, health departments must weigh the potential for stigmatization alongside the public health benefits of WWS for the broader community.[36]

The equity impacts of WWS are also related to public health value. In the United States, approximately 20% of people live in unsewered locations, posing a challenge to equitably distributing WWS' benefits.[37,38,39] Since unsewered communities may also experience other health-related disadvantages related to rurality and lack of broad access to healthcare services, including clinical testing for certain infectious diseases, this challenge can exacerbate existing health disparities. Distributing WWS' benefits is critical to assessing its public health value.

Another important consideration is that the value of WWS comes in part from its role in complementing other ways of understanding population health, rather than as a standalone method. During a disease outbreak, for example, WWS can be useful in providing early detection of a pathogen, leading to more clinical testing, which can then inform evidence-based public health actions or policies like vaccination campaigns.

The public health value of a program is compromised when it does not align with a legitimate public health purpose, including by pressures to pursue uses of wastewater data that are not aligned with a legitimate public health purpose (including by government agencies, such as law enforcement).[2] These pressures can increase when public health emergencies are politicized in ways that are inconsistent with good governance and public health values.[40] Addressing these challenges may require reevaluating potential risks and harms and whether policies and practices (e.g., those related to data ownership) are sufficient to protect the public. In some circumstances, the consequences of such pressures may compromise public health value to the extent that WWS should not be initiated in the first place or should be discontinued if it's already underway.

Pathogen Prioritization
WWS is a flexible and nimble platform that can test for different pathogens in a single sample. However, evaluating whether or not to include specific pathogens involves complex scientific, ethical, and practical considerations, including trend classifications of detected pathogens needed to warrant further action; whether there are effective public health actions an agency can take in response to a pathogen detection; and how communities are likely to be positively or negatively impacted when an agency prioritizes a specific pathogen. Public health institutions and scholars have developed tools to guide WWS pathogen prioritization, but ethical issues are generally implicit. Toro and colleagues, for example, outlined criteria for pathogen prioritization for the 2024 Olympic and Paralympic Games, including “analytic feasibility,” “relevance” to the [Olympic or Paralympic] event, and “added value to inform public health decision making.” [41] Sheth et al describe elements including “public health sensitivity impact level,” encompassing public health threat, urgency to respond, and whether “internal and/or external communications associated with a pathogen detection require special handling or routine reporting.” [42] Guidance for pathogen prioritization, including CDC-developed tools, should explicitly identify potential ethical considerations and include tools for ethical analysis in pathogen.

Community Engagement

Meaningful community engagement is integral to the success of public health policies, programs, and research, including WWS. Both as a process and outcome, the goals of community engagement are ethical goals, including acknowledging past harms, reducing the potential for current and future exploitation, and helping to ensure that policy, program, and research goals respond to the needs, priorities, and circumstances of those most affected by public health problems. [43,44,45]

There are various approaches to community engagement, reflective of different theoretical and methodological orientations, as well as practical considerations and contexts in which it is conducted.[46] While community engagement can help address ethical issues associated with a specific public health problem or intervention, it must be linked to broader trust-building objectives. Communities with the most significant mistrust or vulnerability may be the most critical and challenging to engage. Building relationships and partnerships with, and sometimes among, community members and leaders is crucial. As it is essential to just, equitable, and effective WWS, public health institutions have obligations to and an interest in building the infrastructure, expertise, and ongoing relationship and trust-building required for meaningful community engagement. While financial support is important, successful community engagement also requires an investment of time, commitment, respect, and compassion.[42] It may also be useful to conduct formal research about communities’ knowledge of, attitudes toward, and concerns about WWS, including its ethical dimensions. It’s essential to conduct such assessments in partnership with communities.

Ethical Analysis for Wastewater Surveillance

Ethical issues arise when values are challenged or in tension with each other. Ethical reasoning and analysis are processes of deliberating about the possible reasons for acting or deciding one way or the other and being able to justify or give reasons for the resolution or way forward. [1,28,29]

This framework adopts a method of reasoning and analysis that proceeds by asking questions about the program or decision under consideration. Responses to these questions are informed by the values described in the table above and will help to determine the overall public health value of a WWS program.

Overarching Questions for Ethical Discussion and Analysis of Wastewater Surveillance Activities

Listed below are questions to discuss or consider that raise general ethical considerations for all WWS activities. (Specific questions relating to privacy, stigma, and data stewardship are discussed in Part 2 of this framework.)

For each of these questions, consider the ethical, governance, and scientific values in Table 1.

- What are the public health goals of the WWS program or decision you are considering?
- What are the potential public health benefits of the WWS program or decision you are considering? Who or what groups will benefit from the WWS program or decision you are considering?
- What are the potential harms of the WWS program or decision you are considering? Who or what groups could be harmed by the WWS program or decision you are considering?
- What are the public health implications of not conducting the WWS program you are considering?
- Have affected communities had meaningful opportunities to provide input and raise concerns about the WWS program or decision you are considering?

Part 2

This part of the framework identifies three areas of ethical concern in WWS—privacy, stigma, and data stewardship—that draw on the deliberations of the ENWS-ID Workgroup; focus group discussions with subject matter experts; and review of academic literature, technical reports, and policy documents. The sections below describe the ethical concerns raised by WWS in each of these areas, followed by questions to prompt discussion and guide implementers and decision-makers through the process of ethical analysis relevant to their WWS programs. The final section on public health ethics infrastructure makes recommendations to CDC to strengthen applied public health ethics infrastructure, including in support of WWS implementers.

Privacy

Privacy is related to the ethical concept of respect for autonomy, and is expressed by protecting people's expectations that select information about themselves will not be shared with others.

Health information is often sensitive, and its disclosure (or concerns about its disclosure) can have negative economic, social, or psychological consequences.[47] Rules governing the protection of health information aim to balance privacy interests with the broader social benefits of collecting health data, such as tracking disease and reducing illness and death. While some intrusions on privacy may be necessary to generate these benefits, institutions that collect health information are obligated, in return, to safeguard it. Public surveys of attitudes about WWS suggest people are willing to give up some privacy to promote community health if they are confident that government officials will protect their data privacy and confidentiality.[48] For some, however, a lack of trust in public health or other government institutions, often associated with historic and/or current injustice, may heighten concern about the impact of potential privacy violations.[35,36,40]

Cryptic Lineages

Sequencing pathogen genetic material in wastewater can inform understanding of pathogen genetic change and its possible public health implications. During the height of the COVID-19 public health emergency, some sequencing efforts focused on the emergence of rare SARS-CoV-2 genetic lineages, different from those commonly circulating at the time. Certain lineages identified through genetic sequencing had unclear origins and were thus deemed "cryptic lineages."[49] Such lineages merited scientific attention because their meaning for human health was uncertain.

Efforts to understand cryptic lineages and their public health significance raised concerns about privacy, scale, and how to understand and communicate about findings characterized by considerable scientific uncertainty. Some of the work on cryptic lineages involved upstream and building-specific testing, in certain cases with the goal of individual identification by combining WWS information with other data.[50] During a period of understandable public anxiety about the pandemic, media reports likely intensified privacy concerns."[51,51,52] While the public health intent was to better understand disease, concerns about privacy and data communication highlight the need to engage in effective public health communication and address ethical concerns early in WWS programs.

While we often think of privacy as an individual matter, relating to each person's right to control and protect their own information, it also applies to communities and groups. Like individuals, groups have an interest in controlling and protecting health information about themselves. This protection can help to prevent the harms of exploitation and stigmatization, which can pose more significant risks for groups that are already marginalized or disenfranchised, and who may have experienced historical traumas or exploitations that inform their boundaries around privacy.[53]

Group privacy is highly relevant to WWS; because WWS data are pooled, they can reveal information about groups of people (e.g., those living in a specific neighborhood or facility). Upstream sampling increases data granularity, with the intent of focusing public health action on those most affected by a public health problem (for example, to understand and address an outbreak occurring in a health facility). However, WWS can impact group privacy if detecting certain pathogens results in a particular group or community being labeled as "diseased" or otherwise stigmatized, especially when the group is already vulnerable to prejudice or marginalization.[54]

WWS programs that collect data at a larger scale can minimize intrusions on privacy, since those data are less likely to identify individuals or specific groups, but the public health purpose of WWS may require testing on a smaller scale (for example, to address rural health disparities and promote data equity). [55] However, smaller scale WWS, because it may increase the risk of identifying individuals or groups, involves weighing considerations of justice, equity, and fairness alongside potential privacy-related harms.[56]

To protect privacy, it is essential to consider how WWS information is communicated and to whom. Building and maintaining trust in WWS requires actively and intentionally engaging affected communities.[3] Through community engagement, health departments can mitigate group privacy concerns by providing transparent communication about the goals and benefits of WWS, including the planned uses of the data.

Scale

Scale refers to the geographic boundaries or population size in which WWS sampling is conducted. When WWS is conducted at a large scale, such as in a densely populated city, it is very difficult to identify individuals using wastewater data alone. As the scale narrows to a smaller area or population (for example, a health facility or school campus) the risks to privacy and concerns about stigmatization may increase. Given these risks, WWS conducted at a smaller scale must be justified in terms of a clear public health purpose and benefit to the community, such as early public health action.[25] This justification should be accompanied by timely, focused engagement with affected communities. Nationwide surveys suggest that while there is a high level of public support for WWS at a larger scale where anonymity can be preserved, levels of support are lower for smaller, more specific locations, where concerns about privacy and stigmatization emerge.[57]

Questions for Ethical Analysis, Planning, and Decision-Making

Consider these questions in relation to your WWS program:

- What risks does the WWS program raise for individual or group privacy?
- Does the scale of the program pose privacy risks? If so, what are those risks?
    - If the scale poses privacy risks, is that scale necessary to achieve the public health purpose of the program?
- How can your WWS program safeguard individual or group privacy?
    - What challenges do you face in implementing those safeguards?
    - What resources would help to support your program's efforts to safeguard privacy?
- How can your WWS program safeguard individual or group privacy if data is shared, for example, with researchers or private companies?
    - How will you weigh privacy concerns against the potential public health benefits of sharing data?
    - What resources would help to support your program's efforts to safeguard privacy when sharing data?
- How can your WWS program safeguard individual or group privacy if technological developments pose privacy risks?
    - How will you weigh privacy concerns against the potential public health benefits of technological developments?
    - What resources would help to support your program's efforts to evaluate the privacy implications of technological developments?
- How can findings from your WWS program be communicated in ways that safeguard privacy?
    - How will you weigh privacy concerns against the potential benefits of publicly communicating WWS findings?
    - What resources would help to support your program's public communication efforts?
- How can affected communities raise privacy concerns about your WWS program?
    - What resources would help to support your program's community engagement efforts?

Stigma

Stigma occurs when differences or perceived differences between individuals or groups, including disease status, are deemed socially significant and undesirable. Stigma includes labeling, stereotyping, social exclusion, and status loss.[58,59] Stigmatized individuals or groups can be marginalized and devalued and experience discrimination and harm. Specific groups may have experienced stigma associated with public health interventions, which can heighten concerns about other public health activities, such as WWS.[60] Stigma negatively impacts people's life chances and has been linked to chronic stress, especially for disease-associated stigma.[61] Structural stigma and discrimination, experienced through societal-level conditions, are especially damaging to mental, physical, and community health.[61,62,63] Disease-associated stigma can lead to worse health outcomes, in part because those who experience or anticipate experiencing it may be more likely to delay or avoid seeking the care they need, especially when it occurs in healthcare settings.[64,65]

In public health surveillance, stigmatization is a harm that can occur when individual or group privacy is not protected or information is made public that links an individual or group with a disease, disease risk, or another socially undesirable health condition.[2] Public health surveillance findings can lead to stigma if a disease or outcome is linked to an individual or group. As with privacy concerns, health departments engaging in WWS should carefully consider the scale of the surveillance program and how the data will be shared, as surveillance of larger catchment areas may help avoid stigmatization of groups or communities.[66] On the other hand, WWS surveillance conducted at a larger scale may be less likely to detect differences among groups that might be important for public health action. For example, in some cases, groups that are disproportionately impacted by an infectious disease outbreak will require tailored public health action. Conducting surveillance at a smaller scale can help to ensure these health needs are recognized, measured, and addressed.[6]

Disease-associated stigma can be exacerbated by knowledge gaps and misinformation. Anticipating and addressing misinformation by understanding communities' knowledge and beliefs is an essential aspect of WWS planning. Strengthening relationships with community leaders to develop clear and informative public messaging can help to reduce stigma for affected groups.[66]

To mitigate stigma-related harms, WWS programs should ensure information and data are protected and carefully communicated. Health promotion initiatives and other forms of affirmative health communication about the disease or condition of focus can help to reduce stigma and promote positive healthcare experiences for impacted communities.[64]

Questions for Ethical Analysis, Planning, and Decision-Making:

Consider these questions in relation to your WWS program. Note that many of the questions in the Privacy section will also be relevant to stigma.

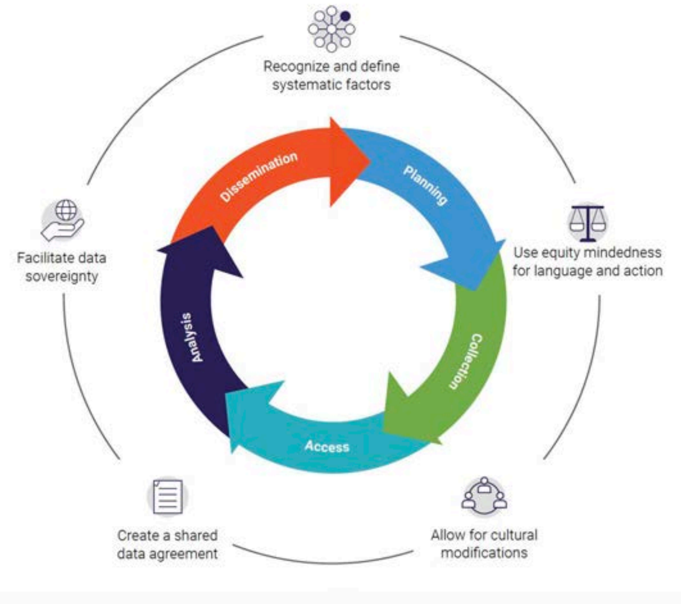
- What stigma-related risks or harms might be associated with or created by your WWS program?
    - What challenges do you face in mitigating stigma-related risks or harms in your program?
    - What resources would help to support your program's efforts to mitigate stigma-related risks or harms?
- Have affected communities identified stigma-related risks or harms associated with or created by your WWS program?
    - How will your WWS Program mitigate these risks or harms?
- How will public messaging strategies about your WWS program mitigate the risks of stigma for affected communities, including risks associated with misinformation?
- How will you assess and mitigate potential stigma-related risks that may emerge because of changes to your WWS program, such a new pathogen target?
- How can affected communities raise stigma-related concerns about your WWS program?
    - What resources would help to support your program's community engagement efforts?

Data Stewardship

Stewardship centers around the judicious use of limited or fragile resources in the interest of the common good.[67] Stewardship is framed by a set of value-based commitments operationalized into policies, processes, and practices that require coordination and cooperation, specialized expertise, and resource investment. [68,69]

Data stewardship applied to WWS includes the general concept of stewardship—being entrusted with something valuable—applied to the ethical, regulatory, technical, and practical aspects of data governance and management throughout the WWS data lifecycle. Stewardship also includes attention to potential uses and misuses of data. This may include harms associated with not using the data for public health action or using the data beyond what was initially intended. A "whole of WWS approach"—premised on the obligations and contributions of all those engaged with WWS—will help ensure data collection, management, analysis, storage, and disposal align with public health value, maximize benefits, mitigate harms, and advance data equity. (See Figure 1).[70,71 72]

Figure 1: Equitable Actions Through the Data Life Cycle



Source: CDC Foundation.

Data stewardship is closely tied to physical sample stewardship. Residual archived samples of untreated wastewater and/or nucleic acid extracts are valuable resources that can be used to improve wastewater surveillance tools and generate additional data. Defined ownership, archiving, and use permissions for these samples can help preserve privacy and trust, and prevent misuse of samples, in communities where wastewater surveillance takes place. It will also be important to update physical sample stewardship plans, as scientific tools and possible uses of wastewater surveillance change over time.

Data stewardship requires that those involved in WWS have the infrastructure and other resources to effectuate stewardship. This infrastructure may include data, ethics, community engagement, or regulatory expertise; investment in STLT data modernization; and tools like model data use agreements. It is crucial to identify who is responsible for different aspects of WWS data stewardship and empower them to perform their roles. Resolving questions of data ownership is critical to data stewardship, and data use agreements may help with this. Concerted effort may be needed to understand and bridge different professional cultures, contexts, and incentives pertaining to data, such as between public health institutions and commercial entities involved in WWS. Federal public health institutions may have a distinct role in data stewardship, providing guidance on standards and bringing a national focus and reach through funding, technical assistance, and convening power.[73]

WWS stewardship and governance may require revision in response to technological change or function expansion. Effective data stewardship must involve continual attention to and analysis of the ethical and other implications of such changes.[74] The challenges and opportunities presented by and expertise needed to understand and address the implications of the current, dynamic, data technology environment cannot be underestimated. Those implications may be positive or negative, with the tradeoffs best evaluated in relation to public health value.

Function Expansion

Some potential uses of wastewater data, such as by law enforcement, are unrelated to public health and can undermine trust in WWS and public health. Function expansion, sometimes referred to as "function creep," occurs when there is "an expansion of the purposes for which wastewater data are used."[2,6] While function expansion can be consistent with ethical public health surveillance, it is important to be vigilant about uses of the data that serve no public health purpose and raise other ethical issues.[75]

WWS data stewardship requires meaningful engagement with communities. Communities must be empowered to participate, which may require guidance on the technical aspects of data governance, collection, management, and security to promote collaborative deliberation.[76]

Tribal Data Stewardship and Sovereignty

Native American and Alaska Native tribes, tribal epidemiology centers, and tribe-serving organizations are essential public health partners—including in WWS. WWS can provide Native American and Alaska Native public health authorities important information to improve the health of their communities. Tribal communities have expertise in human and environmental health, data system design, and data sharing. WWS involving tribal communities must ground approaches to data stewardship in tribal sovereignty and demonstrate trustworthiness, reciprocity, partnership, and understanding of historical and recent injustices, including those related to the use of health-related and other data from tribal communities.[72,76]

Data sovereignty, the ability of indigenous peoples to control their own data, is an important dimension of tribal sovereignty or self-governance.[77] Respect for tribal data sovereignty entails ethical obligations, which, when fulfilled, advance health equity and strengthen tribal and non-tribal public health.[78,79,80] In tribal communities, WWS data stewardship follows from data sovereignty and includes tribal data ownership and proper attribution of data in any published uses.[81] Data stewardship policies and processes must be informed by participatory community engagement.

Questions for Ethical Analysis, Planning, and Decision-Making

Consider these questions in relation to your WWS program:

- What ethical issues are present in the data lifecycle of your WWS program?
    - What resources would help to support your program's efforts to address these ethical issues?
- What data equity concerns, issues, or opportunities are present in data lifecycle of your WWS program?
    - What resources would help to support your program's efforts to advance data equity?
- What infrastructure, processes or agreements are necessary with those who have or are seeking access to WWS data (e.g., commercial entities or researchers)?
    - Has data ownership been addressed in a data use agreement?
    - What resources would help to support your program's efforts to address data access and ownership?
- How can affected communities raise concerns about data stewardship or ownership in your WWS program?
    - What resources would help to support your program's community engagement efforts?

Wastewater Surveillance Public Health Ethics Infrastructure

WWS ethics infrastructure is dependent on and interrelated with public health ethics infrastructure. This framework should be a catalyst for strengthening applied public health ethics infrastructure for WWS across CDC, STLT health departments, water utilities, and other partners. This section makes recommendations to CDC about ethics infrastructure because of CDC's national leadership role in WWS and its obligations to advance ethical public health in the interest of the common good.

Incorporating lessons from the COVID-19 pandemic, this moment is an opportunity to reassess and modernize public health ethics infrastructure as a matter of workforce stewardship and one component of building trust with all communities that public health serves. While CDC has made valuable contributions to public health ethics, at CDC and many other applied public health institutions, political will, visible leadership commitment, and sustained resources are needed to integrate ethics infrastructure into public health programs.[82]

Fundamentally, ethics infrastructure must be rooted in an organizational and professional culture in which ethics is valued and understood as integral to public health success. It should be multifaceted, flexible, and accessible across organizations and systems and may include education, consultation, guidance documents, advisory bodies, communities of practice, staff exchanges, technical assistance, evaluation, and research. Centering trustworthiness, ethics infrastructure in public health institutions and systems, particularly in government, should include independent advisory bodies and other consultative processes empowered to provide transparent, expert, and impartial guidance.

"Advisory bodies and ethics consultation services offer excellent examples of previous efforts at ethics integration; however, ethics should not be thought of as something that exists outside the established public health infrastructure. Rather, the best public health policies are guided by and embody rigorous ethical standards at all levels." As the nation's public health agency with leadership responsibilities in WWS, CDC should consider taking the steps outlined below to renew and strengthen public health ethics infrastructure for WWS.

- Empower existing or hire new staff with public health ethics expertise to have leadership-level influence in policy and programmatic decisions at CDC, including in WWS. These staff should be visible CDC WWS ethics representatives to external organizations, including WWS implementing partners and other government agencies.
- Support an ongoing, systematic evaluation of assets and gaps in WWS ethics infrastructure, including in STLT health departments—to inform strategic planning, and then commit funding and other resources to put these plans into action.
- Leverage the strengths of existing networks and funding mechanisms (e.g., WWS Centers of Excellence) to strengthen ethics infrastructure by disseminating resources, expanding academic partnerships, providing ethics education, promoting ethics consultation, establishing communities of practice, and facilitating peer-to-peer technical assistance.
- Integrate support for ethics-focused activities and evaluation in existing and new WWS-related funding.
- Provide support for additional ethics programs, activities, or resources related to issues or contexts that may raise distinct or complex ethical considerations, such as novel public health emergencies, new technological developments, wastewater-based genomics, or data sovereignty and governance in tribal communities.[83,84]
- Conduct or fund research or evaluation relevant to WWS ethics (e.g., social science research focusing on communities' perspectives on the ethical dimensions of WWS).
- Provide financial, technical, and logistical support for publicly facing ethics activities and resources at CDC and in STLT health departments, including communications, education and training, deliberative activities, and other forms of public and community engagement.
- Convene or facilitate ethics advisory bodies informed by the recommendations of external advisory bodies (such as the National Academies of Sciences, Engineering, and Medicine) or evaluations of assets and gaps in WWS ethics infrastructure.[9,25] This should include assessing whether there is sufficient ethics representation in existing ethics advisory bodies (such as the Board of Scientific Counselors).
- Provide support for advisory structures, including at the national level, that include or are composed of representatives from communities affected by WWS.

Appendices

Appendix A: Case Studies

This section provides three case studies intended for ethical analysis. While informed by the methods used to develop this framework, **these case studies are hypothetical and fictional.** The Overarching Questions for Ethical Discussion and Analysis of WWS Activities and Table 1: Core Public Health Ethics, Governance, and Scientific Values from Part 1 of this document provide tools for analyzing these case studies. The questions for ethical analysis, planning, and decision-making in the privacy, stigma, and data stewardship sections in Part 2 will also be useful in considering the ethical issues raised in the case studies. The cases can be explored individually or discussed as a group and adapted to the needs of those using them. They do not have a predefined solution (although your group may explore reasons for alternative courses of action).[28,85] Rather, they are intended to engage participants in open-ended ethical analysis and deliberation.

Case Study 1

You are an epidemiologist working at a health department (HD) in a mid-sized city. Your role includes interpreting WWS data and making recommendations about public health action. CDC recently issued a health advisory that Pathogen Y is circulating at unprecedented levels in states adjacent to yours. Detectable in wastewater, Pathogen Y is highly contagious and, while asymptomatic or mild in most, can lead to serious illness, particularly in young children, older adults, and medically vulnerable people. Pathogen Y is vaccine-preventable, but vaccine uptake has declined, contributing to more frequent outbreaks. While the HD does not routinely test for Pathogen Y in WWS, it has the capacity to do so. Given the contagious nature of Pathogen Y, health officials decide to proceed with Pathogen Y WWS, proposing targeted vaccination campaigns and other public health measures based on signals from wastewater data. Increasing amounts of Pathogen Y are detected in wastewater from a neighborhood where many new immigrants have settled. Previous engagement with communities in this neighborhood suggests mistrust of government. There has also been expression of anti-immigrant sentiment directed toward the new immigrants on social media, attracting media coverage. It is unclear how widespread this anti-immigrant sentiment is, but community leaders are concerned. The team meets to decide what to do in response to the WWS data.

Case Study 2

You lead a health department (HD) wastewater surveillance program that monitors population trends in respiratory illness. Despite resource constraints, your program has been recognized for its success, including in building trust with the communities you serve. Recently, a private company has approached the HD with resources you don't have and a proposal to expand your program's surveillance to include Pathogen Z, a virus transmitted by mosquitoes. The company has a variety of commercial activities and is looking to expand its drug and diagnostic development portfolio. There have been several locally acquired Pathogen Z cases in your area, but your capacity for Pathogen Z and vector surveillance is limited. The company will contribute resources to fund Pathogen Z WWS and a vector surveillance program. It requests that it retain access to some of the samples for future use. Through its philanthropic arm, the company suggests it might be interested in funding health education and outreach to affected communities, should Pathogen Z become a more significant public health concern locally. You have been asked to advise HD leadership on this proposal.

Case Study 3

You are on a team in a health department (HD) working on improving infectious disease surveillance coverage. A recent increase in clinical presentations of disease Y (caused by pathogen Y; see Case Study 1) has emerged in several different counties in your jurisdiction. K-12 schools have been especially impacted, with high absenteeism rates among students and staff in some schools suspected to be a result of disease Y. With schools as a suspected transmission hotspot, there is increasing pressure on the HD from the mayor's office, school superintendents, and community members, including the parents and guardians of school-aged children, to address disease Y transmission.

HD leadership is leaning toward testing for pathogen Y in wastewater, including upstream sampling through manhole- and facility-level sampling, focusing on K-12 schools. This upstream sampling "zooms in" on a specific contributing community, whether a building, neighborhood, or group of neighborhoods within a larger sewershed. This means that the wastewater signals are more directly connected to the smaller group, which can allow for tailored public health interventions but may have increased risks related to privacy and stigma. There is a lack of consensus among HD leadership about how best to make the information, particularly on upstream sampling sites, useful for schools and others with an interest. The HD is also working to respond to inquiries from the mayor, school superintendents, and parents about the possibility of making school-based information publicly available on the HD's dashboard. Some parents and school staff express concern about the impact of possible school closures, including the interruption of school-based social services, such as meal provision.

Appendix B: Additional Details about Framework Inputs

CDC Wastewater Surveillance Centers Of Excellence Meeting

Centers of Excellence serve as regional leaders in WWS implementation and coordination. They develop and conduct training and provide technical assistance to jurisdictions. From Jan. 30-31, 2024, CDC convened the WWS Centers of Excellence in Atlanta. During this meeting, ASTHO and CDC staff facilitated discussions with meeting participants about ethical concerns in WWS. Participants highlighted issues including scale, access to samples, privacy, stigma, data stewardship, community engagement, transparency and trust, and communications.

Ethical National Wastewater Surveillance–Infectious Disease Workgroup

The Ethical National Wastewater Surveillance–Infectious Disease (ENWS-ID) Workgroup included representation from health departments, academia, utilities, associations, and tribal health. From February-December 2024, ASTHO hosted 7 virtual workgroup meetings focused on key ethical policy and programmatic considerations in WWS. In addition, from May 14-15, 2024, ASTHO hosted an in-person ENWS-ID workshop in Atlanta that also included representatives from academia, STLT health department, water utilities, and professional associations. This workshop focused on developing the framework, including discussing and prioritizing values related to WWS, sharing ethical dilemmas with peers, and analyzing WWS ethics case studies.

Focus Group Discussions

ASTHO conducted three focus groups in April 2024 related to ethical concerns in WWS. Participants included individuals from academia and STLT health departments across the U.S. who were involved in implementing WWS. Discussions elicited multiple ethical concerns about WWS.

Appendix C: Quick Guide to this Framework

Overarching Questions and Values for Ethical Analysis of Wastewater Surveillance Programs

This framework identifies ethical values relevant for WWS and provides questions to guide ethical analysis of a WWS program or decision. The values in Table 1 (page 5) are intended to inform responses to these questions and guide assessment of the overall **public health value** of a WWS program (see p. 6). While ethical questions often do not have "right" and "wrong" answers, values help in deliberating and giving reasons for a resolution or way forward.

For each question, consider how the ethical, governance, and scientific values in the table apply. Values that may be especially applicable are listed beside each question, but others may be important depending on the program or decision you are considering.

Table 2: Appendix C - Questions and Values

Questions	Relevant Values
What are the public health goals of the WWS program or decision you are considering?	Common good; evidentiary standards
What are the potential public health benefits of the WWS program or decision you are considering? Who (or what groups) will benefit from the WWS program or decision you are considering?	Reciprocity; justice, equity, and fairness; common good
What are the potential harms of the WWS program or decision you are considering? Who (or what groups) could be harmed by the WWS program or decision you are considering?	Trust and trustworthiness; justice, equity, and fairness
What are the public health implications of not conducting the WWS program you are considering?	Trust and trustworthiness; common good; resource stewardship
Have affected communities had meaningful opportunities to provide input and raise concerns about the WWS program or decision you are considering?	Trust and trustworthiness; accountability and transparency

Table 3: Appendix C - Approaches to Addressing Ethical Concerns in Wastewater Surveillance

These ethical concerns and additional approaches are described in more detail in Part 2 of the framework.

Ethical Concern	Summary and Approaches
Privacy	WWS can impact individual or group privacy if it reveals information that potentially identifies or stigmatizes them. WWS conducted at a smaller scale may present greater risks to privacy and must be justified by a clear public health purpose. • Approaches include community engagement, public communication about the goals and benefits of a WWS program, and evaluating WWS scale and its privacy implications.
Stigma	Stigma occurs when an individual or group's privacy is not protected or WWS information links an individual or group to a specific disease. Stigma can lead to bias and discrimination and harm to mental, physical, and community health. • Approaches include affirmative health communication about programs or pathogen targets; strengthening relationships with community leaders; and ensuring information and data are protected.
Data stewardship	Data stewardship includes collecting, using, sharing, and storing WWS data for public health benefit. It requires attention to potential uses and misuses of the data, including harms associated with not using the data or using it beyond what was initially intended. • Approaches include addressing data ownership through data use agreements; community engagement with specific attention to data stewardship issues; incorporating data equity principles to identify and address health inequities.

Appendix D: Additional Resources

Table 4: Appendix D - Additional Resources

Resource	Where to Find
Ada Lovelace Institute | Participatory data stewardship: A framework for involving people in the use of data	https://www.adalovelaceinstitute.org/report/participatory-data-stewardship/
American Association of Medical Colleges | The Principles of Trustworthiness Toolkit	https://www.aamchealthjustice.org/our-work/trustworthiness/trustworthiness-toolkit
American Public Health Association | Public Health Code of Ethics	https://www.apha.org/-/media/files/pdf/membergroups/ethics/code_of_ethics.ashx
Centers for Disease Control and Prevention | Public Health Ethics webpage	https://www.cdc.gov/scientific-integrity/php/public-health-ethics/index.html
Centers for Disease Control and Prevention | Principles of Community Engagement (Second Edition)	https://www.atsdr.cdc.gov/community-engagement/php/about/index.html
CDC Foundation | Principles for Using Public Health Data to Drive Equity	https://www.cdcfoundation.org/data-equity-principles?inline
The Community Tool Box | Toolkits	https://ctb.ku.edu/en/toolkits
National Academy of Medicine | Assessing Meaningful Community Engagement	https://nam.edu/programs/value-science-driven-health-care/assessing-meaningful-community-engagement/
The National Academies of Sciences, Engineering, and Medicine | Wastewater-based Disease Surveillance for Public Health Action	https://nap.nationalacademies.org/catalog/26767/wastewater-based-disease-surveillance-for-public-health-action
The National Academies of Sciences, Engineering, and Medicine | Increasing the Utility of Wastewater-based Disease Surveillance for Public Health Action: A Phase 2 Report	https://nap.nationalacademies.org/catalog/27516/increasing-the-utility-of-wastewater-based-disease-surveillance-for-public-health-action
World Health Organization | Guidelines on Ethical Issues in Public Health Surveillance	https://www.who.int/publications/i/item/9789241512657

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